Oncologists' Knowledge, Attitudes and Practices Related to Cancer Treatment Clinical Trials

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Abstract

Native Hawaiians have high incidence rates of cancers diagnosed in late stages and, thus, many might benefit from participation in cancer clinical trials. A survey was developed to explore knowledge, attitudes, and practices of Hawai'i oncologists with regard to cancer treatment clinical trials and Native Hawaiian participation in them. Findings suggest that most cancer specialists are supportive of clinical trials. However, physicians identified a number of barriers to Native Hawaiian participation in clinical trials. Ways to increase participation in clinical trials are suggested.

Introduction

Native Hawaiians have the second highest overall cancer incidence rates and the highest age-adjusted cancer mortality rates in Hawai'i. When compared nationally, Native Hawaiians have the fourth highest incidence rates and the second highest mortality rates for all cancers combined.[1] Higher rates of cancer mortality can be attributed, in part, to the fact that many Hawaiian cancer patients present with late-stage cancer and have poor access to state-of-the-art early detection and cancer care. [2-3]

Advances in cancer treatment and prevention can be achieved through rigorous scientific testing of new cancer treatment and prevention strategies through randomized clinical trials.[4] Randomized clinical trials are controlled experiments that randomly assign patients to one of two or more treatment groups for the purpose of evaluating the most beneficial treatments or cancer detection and prevention methods. Clinical trials offer patients access to state-of-the-art therapy in a research context. [5]

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A limiting factor in advancing cancer treatment and prevention has been inadequate accrual of patients onto clinical trials. Nationally, fewer than 3% of cancer patients enter onto clinical trials, and minority representation is much less.[4] Locally, about 2% of Hawai'i residents diagnosed with cancer participate in clinical trials. [6]

Previous studies have identified barriers to clinical trials. [4-5,7-8] Borrowing from Gotay, we summarize three categories of variables that affect accrual to cancer treatment clinical trials—physician factors, patient variables, and trial characteristics.

Physician Factors. Many physicians do not refer their patients to clinical trials because they lack support staff and/or have concerns about coordination of and compensation for care if a patient joins a clinical trial. Others may believe that the answer to the research question under study is already known or may have a preference for a specific treatment option. Still others may perceive a conflict in role (clinician versus researcher), be concerned that the doctor-patient relationship will be affected, or dislike discussions involving uncertainty, which could undermine a patient's confidence in the physician. Physicians may not refer because they feel a trial is inappropriate given a specific patient's physical, mental, and social conditions. Finally, physicians may be unaware of specific trials available to their patients. [4-5,7-14] The most common physician factor influencing cancer patient enrollment, however, "is that the patient's physician made a decision not to enter the patient in a trial." [8]

Patient Barriers. Patients may not want to enter clinical trials because they do not have enough information about the trial and/or do not have enough time to make a decision about participation. Some patients do not want to be "guinea pig" in a test of an option that might not work or may be more burdensome or cause more side effects than standard treatment. Others distrust Western medicine. Others may have limited insurance or income and or be dissuaded by personal factors such as age, co-morbidities and family opinion. [4-5,8-9,11,13-15]

Trial Factors Accrual is also dependent on the characteristics of the trial, including: trial availability, eligibility, design, informed consent procedures, and mode of presentation of information. [4-5,8,10-11,14,16]

A study of physician knowledge, attitudes, and practices relating to clinical trials was conducted to gain insight into specific accrual issues in Hawai'i. Our objectives were to identify barriers to physician referral of Native Hawaiian patients to cancer clinical trials and to recommend interventions to increase accrual and retention.

Methods

Sample and Survey Distribution

Following approval of the Native Hawaiian Health Systems Institutional Review Board, a questionnaire was mailed to all 88 cancer-specialty physicians practicing in the state of Hawai'i (including medical oncologists, radiation therapists, and surgeons that perform cancer-related surgery), with a stamped, return envelope. Two weeks later, an identical questionnaire was mailed to non-respondents and, beginning two weeks after that, three or more reminder phone calls were made to the remaining non-respondents. Data received by February 1, 2001 were included in the analysis. Survey envelopes were coded so that individual surveys were not linked with names.

Measures

A review of the literature on patient accrual to clinical trials guided the design of the 25-item, cross-sectional survey tool (one-page and double-sided). Demographic items tapped ethnicity, medical specialty, years in practice, training experience, current practice location and size, and percentage of Hawaiian/Part Hawaiian patients in the physician's practice. A definition for cancer treatment clinical trials was provided, and five items queried interest in trials, comfort with discussing trials, number of cancer patients seen each month and, of these, the number of cancer patients engaged in a clinical trial discussion and number of patients that actually entered a trial. The next question asked for agreement (or not) with 17 factors that might deter physicians from discussing a treatment trial with a patient (e.g., trials are not important to my practice, they take too much time, etc.; see Table 4 for a complete list). Another series of items asked how well informed physicians felt about available trials and other cancer-related services, if they would like more information and, if so, which sources would be most influential. Open-ended questions provided opportunities for respondents to write more about barriers and to suggest why few Native Hawaiians participate in trials.

Analysis

Responses were entered into Epi-Info, a public-domain program developed by the Centers for Disease Control and Prevention. Means and frequencies were calculated.

Results

Respondent Characteristics

Completed surveys were returned by 47 (53%) of the cancer specialty physicians. Approximately half of the respondents were medical oncologists and one-third were cancer surgeons; 81% had attended a residency or fellowship program with a strong emphasis on clinical trials (Table 1). Approximately half were Caucasian and only one was Native Hawaiian. Most (76%) were practicing on O'ahu. Half of the respondents had 200 to 1,000 patients in their current practice, and two-thirds of respondents estimated that 5-20% of their patients were Native Hawaiian.

Table 1.— Sample characteristics (n=47)

	n (%)
Primary specialty	
Medical oncology	23 (49)
Surgery	17 (36)
Radiation Oncology	7 (15)
Ethnicity	
Caucasian	24 (51)
Chinese	5 (11)
Filipino	2 (4)
Japanese	8 (17)
Native Hawaiian	1 (2)
Mixed or other	4 (9)
Location of practice	
O'ahu urban	33 (70)
O'ahu rural	3 (6)
Neighbor island	10 (21)
Attended residency or fellowship program with strong emphasis on clinical trials.	38 (81)
How many patients are you responsible for in your current practice?	
< 200	10 (21)
200-500	12 (26)
510-1,000	12 (26)
> 1,000	10 (21)
Approximately how many of your patients are Native Hawaiian?	
< 5%	8 (17)
5-10%	16 (34)
11-20%	15 (32)
> 20%	6 (13)

Percents may sum to less than 100 due to missing data.

Participation in Cancer Treatment Clinical Trials

Approximately two-thirds of respondents said they were "very interested" in cancer treatment clinical trials, and were "very comfortable" discussing trials with their patients (Table 2). Most (85%) of the respondents said that they had discussed clinical trials with their patients in the past year, and on average, these physicians had discussed clinical trials with about 40 patients in the past year. For 11 physicians, however, none of the patients with whom they discussed trials actually entered them. The remaining 29 physicians reported an average of 7 patient entering clinical trials in the past year. The number of patients with whom trials were discussed and the number of patients entering trials differed by specialty, highest for medical oncologists and lowest for radiation oncologists. This is not surprising, since most current clinical trials require radiation oncologists to refer patients to medical oncologists for study registration. [See Table 2 on next page]

Awareness and Use of Cancer-Related Services

Only about half (53%) felt "very well" informed about available cancer treatment clinical trials, and 60% were interested in receiving more information on trials (Table 3). More than half (60%) preferred getting this information from the Cancer Research Center of Hawai`i (CRCH).

Respondents were asked if they were aware of and had used three cancer-related programs sponsored and funded by the National Cancer Institute (NCI): the Cancer Information Service (CIS), Physician's Data Query (PDQ), and Cancer Research Center of Hawaii (CRCH) (Table 3). The CIS operates a toll-free phone line with workers providing outreach and education services to health

Table 2.— Interest, comfort, and participation in clinical cancer treatment trials (n=47)

	n (%)
What is your level of interest in cancer treatment clinical trials?	
Very interested	30 (64)
Somewhat interested	13 (28)
Not at all interested	3 (6)
What is your comfort level in discussing cancer treatment clinical trials with your patients?	
Very interested	30 (64)
Somewhat interested	13 (28)
Not at all interested	3 (6)
Per physician, newly diagnosed cancer patients seen each month	
10-100	20 (43)
101-200	9 (19)
> 200	16 (34)
Have discussed clinical trials with patients	
Medical oncologists (n=23)	22 (96)
Surgeons (n=17)	12 (71)
Radiation oncologists (n=7)	6 (86)
Overall	40 (85)
Per physician (n=40), estimated number of cancer patients, in past year, with whom clinical trials were discussed	
Medical oncologists (n=22)	52/year
Surgeons (n=12)	30/year
Radiation oncologists (n=6)	18/year
Overall (n=40)	40/year
Per physician (n=24), estimated number of cancer patients who entered clinical trials.	
Medical oncologists (n=16)	8/year
Surgeons (n=10)	7/year
Radiation oncologists (n=3)	1/year
Overall (n=29)	7/year

Percents may sum to less than 100 due to missing data.

Table 3.— Awareness and use of cancer-related information sources and services (n=47)

	n (%)
Do you feel that you are well informed about available cancer treatment clinical trials?	
Very well informed	25 (53)
Somewhat informed	16 (34)
Not at all well informed	2 (4)
Wants information on cancer trials	28 (60)
From which sources?	
Cancer Research Center	28 (60)
Tumor boards	17 (36)
Conferences	15 (32)
Journals	14 (30)
Internet	13 (28)
One-hour meetings	9 (19)
CD-ROM	8 (17)
Cancer Information Service	8 (17)
Grand rounds	5 (11)
Other	7 (15)
Has used or referred to:	
Cancer Information Service	28 (60)
Physicians Data Query (PDQ)	29 (62)
Support staff from CRCH	27 (57)
Cancer support groups	39 (83)

Percents may sum to less than 100 due to missing data.

care providers. They also offer cancer information (including information about clinical trials) to the general public, patients, and family members. Most (81%) of physicians said they were aware of CIS, and 60% had used it. The PDQ is a Web-based resource that provides up-to-date reviews of the scientific literature related to cancer prevention, detection, treatment, supportive care and genetics, as well as inventories and contact information for clinical trials and cancer organizations. In all, 81% of respondents said they were aware of PDQ and 62% had used it. The CRCH, through its Minority-based Community Clinical Oncology Program, employs support staff available to help physicians present information about cancer clinical trials to patients and to assist with the informed consent process. Among our respondents, 79% were aware of this program and 57% had accessed it. Additionally, 94% said they were aware of local support groups for cancer patients and their families, and 83% had referred patients to support groups.

Barriers to Discussing Clinical Trials

Physicians were asked to agree (or not) with statements related to physician, patient, and trial factors that might deter them from discussing trials with their patients (Table 4). An open-ended question allowed them to give reasons why Native Hawaiian participation in trials may be particularly low.

Physician Factors. Ten physician-related barriers were included in the survey, and agreement that these items were barriers was generally low. In fact, only four of the ten physician factors were seen as deterrents by 25% or more of the responding physicians. Of these, three items had to do with time and cost (not having enough support staff to manage trials, not feeling adequately compensated, and feeling that it was too difficult and time consuming to provide informed consent). The fourth physician factor concerned physician preference for one of the treatment arms of a study. Additionally, 19% felt that available clinical trials were not important to their practice.

Patient Factors. Of the four patient factors, 25% or more of physicians agreed that three served as deterrents to trial accrual—patient refusal, patient co-morbidities, and lack of transportation.

Trial Factors. More than 25% of respondents saw each of the three trial factors as deterrents. They felt clinical trials were too time consuming, were not innovative, and did not address questions relevant to their patients.

Factors Deterring Native Hawaiian Participation. The open-ended question elicited a number of reasons for low clinical trial participation by Native Hawaiians. Several referred to cultural factors, e.g., that Native Hawaiians have a cultural bias against Western medicine (n=5), fear diagnosis and therapy (n=3), and prefer to try Hawaiian traditional remedies or other alternative approaches (n=4). Two physicians commented on the difficulty in getting informed consent, and one of these physicians wrote, "It's hard for a physician to 'talk story' long enough for Native Hawaiian patients to feel comfortable joining a trial." Related to this were two comments on quality of life. A physician wrote that, to Native Hawaiians, "quality of life is much more important than quantity." Another noted that Native Hawai-

Table 4.— Barriers to discussing clinical cancer treatment trials with patients (n=47)

	n (%)
Physician factors	
Not have enough support staff	22 (47)
Preference for one of the treatment arms in the study	18 (38)
Providing informed consent too difficult, time consuming	12 (26)
Not adequately compensated.	12 (26)
Trials not important in my practice.	9 (19)
Not comfortable subjecting patients to trials.	2 (4)
Conflict between my role as clinician vs researcher	3 (6)
Explaining treatment arms undermines patients' confidence in me.	3 (6)
Trials interfere with the doctor/patient relationship.	1 (2)
Concerned my patient may transfer to another doctor.	1 (2)
Patient factors	
Patients refuse to participate.	23 (49)
Patients have co-morbidities.	18 (38)
Patients lack transportation.	12 (26)
Patients lack insurance.	8 (17)
Trial factors	
Clinical trials are too time consuming.	15 (32)
Clinical trials not innovative.	14 (30)
Trials do not address questions relevant to my patients.	12 (26)

ians were reluctant to join clinical trials because they had "witnessed suffering and lack of improvement from chemotherapy in their families."

The second category encompassed access issues, including socio-economic barriers (n=4) and lack of Native Hawaiian physicians, especially in cancer specialties (n=1). A third category concerned education, e.g., Native Hawaiians lacked information about cancer and screening recommendations (n=3) and that they had a poor understanding of the process and benefits of clinical trials (n=5).

A physician commented that, "Most people, including Native Hawaiians, would rather go with proven results," while another cited "guinea pig" mentality. Two noted that Native Hawaiian patients often presented with a number of co-morbidities that made them ineligible for trials. Another physician wrote that, "Clinical trials may not be the best prescription for the patient."

The final category encompassed physician issues, e.g., clinical trials are not offered by doctors (n=5), physicians are not interested in clinical trials (n=1), and clinical research is not supported by the medical community (n=1).

Discussion

Our findings suggest that most cancer specialty physicians feel comfortable discussing clinical trials with patients and are aware of the services provided through NCI and CRCH. However, generalizations must be tempered since not all physicians returned surveys and we do not know the knowledge, attitudes, and practices of non-respondents. However, since statistics show that participation in clinical trials is low, it appears that clinical trial participation rates can be improved.

Barriers to clinical trial accrual identified by Hawai'i physicians were similar to those reported in the literature. Additionally, Hawai'i does not have an integrated statewide system for implementing clinical trials, most cancer specialists practice on O'ahu (reducing opportunities for participation by neighbor islanders), and physicians on O'ahu practice at a variety of hospitals with varying levels of support for clinical trials activities.[6]

Programs to decrease barriers to clinical trial participation should be implemented. The Governor's Blue Ribbon Panel on Cancer Care in Hawai'i, which issued a report in 2001, made two suggestions that likely would help increase accrual to clinical trials.[6]

- Hawai'i should establish an Outpatient Cancer Center, located near major hospitals, that would support the development of a comprehensive clinical treatment program in the state. This center would offer care coordination, health education, expedited assessments (e.g., lab and imaging services), and multi-disciplinary treatment planning, as well as clinical trial support. This one-stop-shop approach would increase the efficiency and comprehensiveness of cancer care, and save patients from having to make and keep multiple appointments in several different facilities.

- A statewide clinical trials system should be developed, supported by this Outpatient Cancer Center and CRCH. With this, Hawai'i could apply to become an NCI-designated Comprehensive Cancer Center, which would result in an increased availability of new treatments and clinical trials. A coordinated, statewide system for accrual to clinical trials should offer support staff available at times and locations convenient to patients, address physician compensation concerns, and provide opportunities for public recognition at conferences and professional dinners.

Other strategies may be fruitful as well. The literature describes ideas for increasing accrual of minority Americans to clinical trials,[5,8] several of which may work in Hawai'i.

- Native Hawaiian health care providers could be enlisted to help recruit Native Hawaiian participants to clinical trials. Unfortunately, at the present time, only 4% of Hawai'i physicians are Native Hawaiian and only one oncologist is Native Hawaiian (Else et al, 1997) The oncology nurses society includes Native Hawaiian nurses who may also agree to assist in recruitment. Scholarship programs, established to increase the number of Native Hawaiians in the health professions, are helping to correct this disparity.

- Educational programs for clinical trials should provide culturally appropriate informational materials in lay language and should be distributed at professional, church, and community meetings and at health fairs and sporting events. Public service announcements should be provided to Hawaiian music radio stations, newspapers, and newsletters of Native Hawaiian organizations.

- Many individuals are influences by personal testimonials, and peer counseling has been effective in some minority communities. Such a program in Hawai'i could link trial-eligible individuals with current and former participants in clinical trials.

Although most cancer patients in Hawai'i do not participate in clinical trials, this study showed that Hawai'i oncologists have positive attitudes about the value of clinical trials for their patients.

We have suggested a number of ways that the process of clinical trials accrual might be enhanced. The implementation of such changes, coupled with continuing physician support, has the potential to expand clinical trials participation for local cancer patients, Native Hawaiians in particular.

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